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Parents' experiences of managing their child's diabetes using an insulin pump: a qualitative study

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What's new?

- This is one of few studies to explore, in-depth, parents' experiences of managing their child's diabetes using an insulin pump.

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- By using an open-ended exploratory design, we highlight hitherto unrecognized issues for parents. These include unanticipated burdens and additional caregiving responsibilities arising from using a pump.
- We provide recommendations for how, in future, parents could be given more education and support prior to and subsequent to using a pump.

Abstract

Aims To better understand the impact of continuous subcutaneous insulin infusion delivered by pump on parents who care for young children using such pumps. To help interpret the psychological outcomes reported in quantitative research and inform future provision of support to parents.

Methods We conducted in-depth interviews with 19 parents of children (aged ≤ 12 years) with Type 1 diabetes who used an insulin pump. Data were analysed thematically.

Results Parents reported multiple benefits from using insulin pumps, including: no longer having to administer painful injections; fewer restrictions on the frequency, timing and carbohydrate contents of snacks and meals; and improvements in family life and their child's glycaemic control. Parents liked and felt less anxious about using bolus calculators to determine insulin doses; however, parents also described undertaking additional and unanticipated work to manage their child's diabetes using a pump. This included performing more blood glucose tests to calculate insulin doses for snacks and to address their concerns that the pump increased their child's risk of hypoglycaemia. Some parents reported doing additional blood glucose checks because they could adjust pump settings to better manage hypo- and hyperglycaemia.

Conclusions Parents liked and perceived benefits for their child and themselves from using an insulin pump; however, parents would benefit from being made aware of the additional work involved in

using a pump and also from education and support to address concerns about hypoglycaemia. Better measures to evaluate parents' experiences are also recommended.

Introduction

Intensive insulin treatment is recommended to achieve optimum glycaemic control and reduce the risk of children with Type 1 diabetes developing complications [1]. This can be achieved using multiple daily injections or continuous subcutaneous insulin infusion delivered via a pump [2], which often incorporates an automated bolus calculator to calculate insulin doses [3]. Improvements in technology and the capacity to deliver small, accurate doses has meant that pumps are recommended for [4] and increasingly used by younger children, those with suboptimum glycaemic control and/or who experience frequent episodes of hypoglycaemia [5–6]. The benefits of pump therapy for children continue to be debated with regard to the extent and duration of improvements found in trials versus observational studies; however, in general, research has shown that children who switch from multiple daily injections to pumps experience improvements in HbA1c, reductions in the frequency of severe hypoglycaemia, lower rates of ketoacidosis and improved quality of life [5,7–9] with many benefits maintained in the long term [10].

While the benefits of continuous subcutaneous insulin infusion for children are reasonably well established, quantitative research investigating its impact on their parents has produced inconsistent findings. Some studies have reported improvements in parents' quality of life, reductions in stress and worries about hypoglycaemia, and high levels of satisfaction when their child uses a pump [11–13], but others have shown no differences in parental quality of life or parenting stress, when comparing parents of children using pumps or multiple daily injections [14–17]. Most qualitative research exploring parents' accounts has been limited in focus [13,18] and/or restricted to those with adolescent or very young children [19,20]. To date, only one other study has used in-depth interviews

to explore parents' experiences of managing young children's diabetes using a pump and this study was undertaken in the USA more than 10 years ago [21]. That ground-breaking study adopted a broad approach by exploring parents' decisions to move their child onto the pump and their experiences during transition from multiple daily injections, before reporting their accounts of using a pump and its impact on their child and family members' quality of life.

To supplement the limited qualitative research undertaken to date, and to better understand the impact of using pumps on parents, we conducted an interview-based study in parents who cared for a child aged ≤ 12 years with Type 1 diabetes using an insulin pump. In this study we explored parents' experiences of using an insulin pump to manage their child's diabetes, including their views about the benefits and challenges for themselves and their child. Our objectives were to aid interpretation of the psychological outcomes reported in quantitative research undertaken with parents and to inform provision of support to future parents. Our study focused on parents' perspectives and experiences because, in our target age group (children aged ≤ 12 years), parents assume over-arching responsibility for their child's diabetes management tasks [22].

Methods

Rationale for a qualitative study design

Qualitative approaches are recommended when little is known about the area of investigation [23]. Rather than seeking to quantify an issue or test a pre-determined hypothesis, qualitative approaches aim to open up and explore new lines of enquiry by using flexible and open-ended methods of data collection which provide participants with opportunities to raise and discuss issues they perceive as salient, including those not anticipated at the study's outset [23]. As such, qualitative approaches offer a powerful and effective method for uncovering people's perspectives, understanding and experiences. In this case, we looked at parents' experiences of managing their child's diabetes using

an insulin pump, this being an under-researched area in the UK, where pump therapy for paediatric patients was implemented more recently than in other countries.

Sample and data collection

As part of a broader study exploring parents' experiences of caring for a child (aged 3–12 years) with Type 1 diabetes [24,25], we recruited 19 parents (13 mothers and 6 fathers) of 14 children using insulin pumps. These parents were recruited from four Scottish paediatric diabetes clinics, where ~30% of children (aged ≤ 12 years) now use insulin pumps, and where comprehensive education and instruction on the use of these devices is provided (Fig. 1).

Recruitment packs were distributed by health professionals to parents attending clinics who met the eligibility criteria (see below). Parents were recruited using an opt-in procedure and purposive sampling was used to ensure diversity in the final sample in terms of parental demographic and child demographic/disease characteristics (Table 1). Sampling was also informed by an Advisory Group convened at the start of the study, which comprised health professionals (paediatric diabetes consultants, diabetes specialist nurses), lay representatives (parents of children with Type 1 diabetes), policy makers and representatives from charitable organizations supporting people with diabetes. Group members recommended that our broader sample reflect the proportion of parents of children using pumps in the four clinics and that only parents who had at least 6 months experience of managing their child's diabetes using a pump should be interviewed to ensure that they could reflect on their experiences of using the device.

Recruitment and interviews were staggered to permit concurrent data collection and analysis, in line with the principles of Grounded Theory research [26]. Recruitment was stopped when no new findings or themes were identified in the new data collected.

A total of 14 interviews (five involving both parents, nine involving one parent) were conducted in home settings between November 2012 and August 2013 by D.R., an experienced qualitative researcher. Interviews were informed by topic guides developed in light of literature reviews, original research questions, clinic observations undertaken prior to data collection and inputs from advisory group members, including parents of children with Type 1 diabetes. In line with our inductive approach, the topic guide was revised to take account of emerging findings following analysis of early interviews. Relevant areas explored in the interviews are shown in Fig. 2. Interviews averaged 120 min in length, and were recorded (with consent) and transcribed in full.

Data analysis

A thematic analysis using the method of constant comparison [26] was undertaken by two experienced qualitative researchers, D.R. and J.L. To ensure analytical rigour, each researcher independently read and re-read each interview before cross-comparing all interviews to identify issues and themes that cut across parents' accounts. Regular meetings were held to compare interpretations, reach agreement on recurrent themes and to develop a coding framework which captured original research questions and emerging findings. All data were coded by D.R. with segments checked by J.L. to ensure accuracy. NVIVO, a qualitative software package (QSR International, Doncaster, Australia), was used to facilitate data coding/retrieval, and coded datasets were subject to further in-depth analysis. Clinical colleagues and co-authors on the paper, and members of the Advisory Group, also reviewed, confirmed and helped inform the interpretation of findings to ensure that the study's implications and recommendations were relevant to clinical practice. Data were tagged using unique identifiers. The South East Scotland Research Ethics Committee 01, NHS Lothian approved the study (reference: 12/SS/0071).

Results

All parents described how their child had switched to an insulin pump after they had asked to join a waiting list or because they had been encouraged to do so by health professionals. Parents also reported that their child had been issued with a pump free of charge from the National Health Service,

with most pumps supplied by Medtronic, and that all children undertook self-monitoring of blood glucose rather than continuous glucose monitoring. Irrespective of the route by which their child obtained a pump, or for how long their child had used the device (Table 1), all parents highlighted similar issues and experiences. As detailed below, while all parents described positive impacts of pumps on their own and their children's lives, they also highlighted unanticipated burdens arising from using this technology.

Benefits of insulin pumps

Less injection-related pain and a more flexible lifestyle

Parents reported how multiple daily injection regimens had required them to inject up to seven times each day and how both they and their child had felt very distressed and upset when insulin had had to be administered: 'she braced herself every time and I hated it' (P06). In contrast, after switching to a pump, parents described feeling relieved because their child was less likely to bruise or develop lipohypertrophy and because they no longer had to administer multiple, painful injections: 'the pump made things a little easier because he hated the injections so much... when he went onto the bolus that was five, six times a day and that is just traumatising to see' (P04).

Most parents also described how multiple daily injections had been a very restrictive regime where they had had to administer long-acting insulin injections at specific times, which often involved setting alarms and interruptions to sleep. Others reported having had to restrict the frequency, timing and carbohydrate content of their child's snacks to minimize the number of injections required and having had to ensure that their child ate sufficient carbohydrate after administering meal-time injections. As P08 pointed out, these stringent demands could result in their child becoming distressed or angry and parents feeling stressed or panicked:

'she hated the injections, well she wanted a bar of chocolate or she wanted this or that, but its "you can't have that" ... then they have to eat at certain times of the day, "you're going to have this for dinner, therefore I'm going to give you this amount of insulin before your dinner" and then you get so far through dinner and she goes, "I'm not hungry, I don't want to eat that" and then panic sets in, "but you need to eat it, you need to eat it"'.

In contrast, parents reported that using the pump had resulted in mealtimes and other occasions when food was consumed being much less stressful because the device had enabled their child to develop 'a more natural relationship with food' (P06). As several parents described, this was because a child using a pump could eat a meal or snack without a corresponding need to inject: 'if he does have something in-between [meals] we can, rather than having to give him an injection, he can just, we give him a wee bolus' (P10). Parents also described feeling relieved because they no longer had to impose restrictions on the amount of carbohydrate contained within their child's snacks:

'when he was on the injections he would have to have a morning snack and em that was covered by his background insulin. You didn't give him insulin at that point, so he was only allowed about 10 grams ... you know that was quite hard to be very strict whereas when he went on the pump, because you just put in... the number of what he's eating and he can more or less eat anything he wants then at that point'. (P12)

All parents highlighted how family life had been transformed as a result of the pump, as it provided them with greater flexibility to eat a broader range of foods (P06). For example, several parents described no longer having to stop or discretely eat snacks such as chocolate or ice-cream in order to avoid distressing a child excluded from indulging in a similar way. In other instances, parents highlighted how family life was no longer constrained by having to administer background insulin at specific times of the day and because eating outside the family home was 'much easier because you're not planning, you've not got to think about lunchtime, where can we go for an injection' (P02). Others

also suggested that using a pump was less stigmatizing than using injections because 'it's [pump] discrete, socially it's much easier. Nobody notices, you know' (P14), and how this allowed a more relaxed and spontaneous family life as a consequence.

Parents also described how they were able to better manage planned physical activity by using temporary basal rates, which meant they no longer had to restrict their child's activity to fit injection times. Others reported that they were better able to manage their child's diabetes during periods of illness when blood glucose readings could fluctuate, because using the pump meant that they could temporarily suspend the delivery of insulin: 'When he's sick things just go haywire and if you've got the pump you can turn it off. You're not meant to turn it off for any length of time, but I mean you can pull the plug at that minute, you don't have a background insulin going on that you can't deal with' (P12).

Better control

Many parents reported having struggled to control their child's blood glucose levels using injections, including P09 who had used half-unit pens to inject her 12-year old son and who recalled having been unable to sufficiently fine-tune insulin doses because, 'if we did increase the dose he was quite likely to have hypos'. Similarly, P12 recalled having been unable to correct her two-year old son's high readings using injections because she was unable to administer a small enough dose and instead described her improvised attempts to do so by restricting his food intake: 'if he was running high at lunchtime ... I would drink some of the juice before I gave it to him... silly things like that because I couldn't adjust it by giving insulin'.

Virtually all parents described how, after their child had switched to a pump, they had been able to achieve more stable blood glucose readings because the device was capable of delivering very small and precise insulin doses: 'So you could get much more accurate [insulin] delivery to what she'd

actually eaten' (P06). The precision of insulin delivery also meant that parents felt better able to correct their child's high blood glucose readings to achieve clinically defined targets, including, P03, who highlighted the benefits of her 4-year-old son moving onto a pump as follows:

'you have so much more control, you know, you haven't got to give him an injection and stand there with a cup of [diluting juice containing sugar] because he might go hypo... because you couldn't give a small amount of insulin... if we need a quarter of a unit, this pump will only give him a quarter of a unit.'

Benefits of bolus advisors

Several parents also described lacking confidence in their mathematical skills and having worried about the consequences of miscalculating doses when using multiple daily injections: 'you panic 'cause I'm thinking, I'm going to kill him 'cause I'm going to give him twenty [units], it's in your head, all the time thinking, "you've got to get this right, don't be stupid"' (P04). However, after switching to the pump, many of these parents described benefiting from using the bolus advisor to calculate doses to take account of different ratios or correction factors applied at different times of the day. In particular, parents reported feeling less worried about either themselves or other caregivers (e.g. school/nursery staff) administering too large a dose as the bolus advisor would determine whether and what quantity of insulin was needed: 'it'll tell you whether or not it'll give him a corrective bolus for that high ... but it won't give him anything if he's got enough active insulin' (P03).

More work for parents and other caregivers

While most parents reported a plethora of benefits arising from using a pump, many also described taking on new responsibilities and additional work which they had not foreseen or been prepared for at the outset. By virtue of their child being able to eat a more flexible diet when using a pump, and

because they could administer very small amounts of insulin, parents described how they, or their child's teachers, now needed to perform more blood glucose readings in order to calculate bolus doses to cover snacks as well as at mealtimes. While some parents reported that their child's teachers were more willing to supervise use of the pump: 'because they're not seeing the needle, they are much happier to look after her' (P06), others described not anticipating that teachers would be reluctant to use the pump and how they regularly had to attend their child's school to change pump settings as a consequence: 'her badminton's at four, so I go into the school at two o'clock to reduce her basal rate as I don't want to put more and more on them [teachers]' (P11).

More work to address perceived risks of hypoglycaemia

In other examples, parents highlighted how their child had poor awareness of symptoms of hypoglycaemia and described feeling worried that the constant drip-feed of insulin administered using the pump would exacerbate the likelihood of undetected episodes of hypoglycaemia, particularly at night-time. While most acknowledged that these were irrational fears which ran contrary to advice received when their child began using the pump, several parents spoke about taking preventive action to address their concerns. These included sleeping next to their child, using a baby monitor to detect unusual sounds or taking action to 'check them more often' (P11). A pertinent example was provided by P01, who described living with 'the fear that she's not going to wake up' and how she now performed more checks on her daughter's blood glucose: 'she gets checked at half past seven when she has her supper... and I check her at nine pm when she's asleep and if she's running low then I'll put her on a temporary basal for a couple of hours'. In addition, P01 also reported how her sleep was disrupted by 'checking her in the night because you don't want her dropping.'

More work because parents can do more to manage their child's diabetes

Parents also described being surprised by how additional monitoring had helped them identify hitherto undetected low blood glucose readings which, coupled with their ability to alter basal rates of insulin

infusion, gave them a further impetus or rationale for continuing to perform more frequent checks. For example, P12, reported how:

'we were doing a lot of night time checks and I hadn't realised it varied as much so that was problem for me... I couldn't stop testing because I was now aware how much it fluctuated and I felt this, not duty, but you wanted to try and pick up on a hypo almost before it happens'.

Similarly, by virtue of knowing that they could more precisely alter basal insulin rates to better control their child's blood glucose levels, other parents described now feeling compelled to perform additional tests to monitor and, if necessary, correct high blood glucose readings. This included P02, who described setting an alarm specifically to ensure her daughter began each day within recommended targets:

'I wouldn't leave her, why would I leave her to run high all night, that just doesn't make sense [...] That's why I do the half five [am] check for her, because when she's high at half five and I can correct it and I know she'll be perfect for breakfast whereas if I wait until ten past seven then she's high.'

Discussion

This is one of very few studies to have explored parents' experiences of caring for a young child with Type 1 diabetes using an insulin pump. As others have shown [13,21], parents described several benefits arising from using a pump, including: no longer having to administer painful injections; having flexibility for their child to eat whenever and whatever they chose; and being able to fine-tune their child's glycaemic control. In keeping with findings from earlier research [21], parents in the present study also reported how managing their child's diabetes using an insulin pump often resulted in them performing more blood glucose monitoring to detect hypoglycaemia; however, our findings also illustrate how parents faced additional, unanticipated burdens hitherto unreported in the literature.

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These include having to undertake work to accommodate their child's ability to eat more flexibly and, for some, having to support their child at school. Furthermore, parents described feeling obliged to undertake more blood glucose monitoring, including at night, ostensibly because they perceived the pump as enabling them to better manage risks of hypo and hyperglycaemia.

Our findings help to explain why parents in other studies [11–13] report improvements in quality of life after their child switches to using an insulin pump. Specifically, parents in our study perceived that using a pump helped to improve their child's quality of life and, by proxy, their own, because, for example, they no longer had to administer painful injections or restrict food choices. However, our findings have also highlighted how using a pump to manage a child's diabetes can have potentially adverse impacts on parents' quality of life. Some parents, for example, described feeling very worried that the pump might expose their child to an increased risk of hypoglycaemia and, as a consequence, deciding to undertake proactive blood glucose testing, including waking at night, to maintain recommended targets. By illustrating the positive and negative impacts of using pumps, our findings help explain why some randomized trials have shown no differences in quality of life measures for parents of children using pumps or multiple daily injections [14–16].

We have also highlighted how parents benefited from, and described feeling less concerned about miscalculating insulin doses when using the bolus advisor function on their child's pump. This finding resonates with those from studies undertaken with adults with Type 1 diabetes, which have reported that adults like being able to more accurately determine insulin doses using bolus calculators [27] and experience reductions in stress from no longer having to perform complex mathematical calculations [28,29].

The present findings suggest that parents contemplating a pump for their child would benefit from being made aware of what additional work (e.g. to give a bolus for snacks and to change pump settings at school) they might have to undertake in order to help them make an informed decision. This advice could be reiterated to parents after they have decided to switch to a pump and during the

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preparation phase before their child begins to use the device. Our findings also suggest that parents of children who use pumps could benefit from advice about when and how often to perform blood glucose monitoring. In addition, health professionals could use routine consultations to ascertain whether parents express concerns about basal insulin infusion and hypoglycaemia and, if necessary, offer advice/education to alleviate their anxieties.

The present study is strengthened by its use of an open-ended exploratory design which enabled parents to raise and discuss issues most salient to them. A potential limitation is that ~50% of our sample were well-educated (graduate level) parents who may have been more empowered to ask for a pump, may have been better at diabetes management, and/or whose healthcare professionals felt were better candidates for this technology. Hence, researchers should consider involving more parents of children with a broader range of vocational and educational experiences. As reported above, all children used blood glucose self-monitoring equipment; however, to reflect technological advances [30], we recommend that future studies include parents of children using technologies such as continuous glucose monitoring equipment and/or closed loop systems. Given our finding that schools appeared to differ in the level of support offered to children using insulin pumps, further research could be conducted in schools to explore which policies are used and how these are interpreted and acted upon by staff. We also recommend that quantitative research is undertaken, using scales and questions informed by the present findings, to better and fully capture the benefits and burdens on parental quality of life of using a pump to care for a child with diabetes. Such data could also be used in future economic evaluations of continuous subcutaneous insulin infusion in children.

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Competing interests

K.B. sits on the global advisory board for Roche Diagnostics and on the Roche European Insulin Delivery Systems advisory board as well as the CHOICE advisory board for Lifescan. She has received honoraria for speaking from Roche, Astra-Zeneca, Lifescan, Janssen, AbbVie, Animas and has acted as external expert for Lifescan and Roche on clinical research trials. There are no other conflicts of interest.

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FIGURE 1 Education offered to parents and children before and after being issued with a pump.

FIGURE 2 Relevant areas explored in interview topic guides.

Table 1 Demographic characteristics of interview participants and their children

Characteristic	<i>n</i>	Mean \pm SD (range)
Parents (<i>n</i>=19)		
Mothers	13	
Age: all parents, years		40.1 \pm 3.7 (34--44)
Married / living with partner	18	
Ethnicity: white British	19	
Current employment status		
Full-time	7	
Part-time	5	
Full-time carer	4	
Not working	2	
In education	1	
Occupation		
Professional	4	
Semi-skilled	4	
Unskilled	6	
Full-time carer / not working	5	
Education: those with academic degrees	9	
Children (<i>n</i>=14)		
Female	6	

Age: all children, years	8.4 ± 2.8 (3–12)
Age at diagnosis, years	3.8 ± 2.1 (1–6)
Length of time on pump, years*	2.2 ± 1.2 (1–4)
Children in full-time education	12

HbA1c: all children

mmol/mol	62 ± 8.5 (44–75)
%*	7.8 ± 0.8 (6.2–9.0)

*

Figure 1

Pre-insulin pump process:

- Families who express an interest in a pump are invited to complete documentation and placed on a waiting list.
- Families are invited to a pump demonstration session before being referred for psychological assessment.
- Prior to using the pump, families are assessed by the dietician and diabetes specialist nurse to ensure accuracy of carbohydrate counting, frequency of blood glucose self-monitoring and to gauge their readiness for pump therapy.
- Further documentation and preparatory materials (including the pump) are delivered in advance of starting pump therapy.

Insulin pump start process:

- Parents and children attend a pump education course run at the diabetes centre where they are

given instruction in how to use the device with saline. Education includes: the need to undertake frequent blood glucose monitoring; how to calculate/administer bolus doses; managing hypo- and hyperglycaemia; blood glucose targets; physical activity; and cannula insertion.

- The child and their parents' progress is reviewed after 1 week and, depending on a satisfactory outcome, insulin therapy is initiated.
- Families are advised that telephone support is available and regular follow-up calls are made by the diabetes team.
- In the following weeks, families are invited to review progress in further sessions with the diabetes specialist nurse and are requested to provide pump downloads for review by members of the diabetes team.
- Ongoing education is provided along with further follow-up at clinic, including reviews of pump downloads.

Figure 2

- Parents' views about, and experiences of, using a multiple daily injection regimen to manage their child's diabetes before switching to an insulin pump.
- Parents' perceptions of, and views about, the insulin pump before their child began to use the device.
- Parents' accounts of managing their child's diabetes using the insulin pump, including their views about eating and mealtimes, physical activity, hypo- and hyperglycaemia.
- What are parents' experiences of other people providing care for their child when they have switched to using an insulin pump? (including, other family/friends, at school)
- What are the benefits and challenges involved in managing a child's diabetes using an insulin pump?